

Testimony of Prof. Felicia Cohn
on behalf of the American Geriatrics Society
before the Commerce Committee of the
United States House of Representatives

March 6, 1997

Summary of Statement

The American Geriatrics Society agrees with Senate Bill #304. An official policy statement, approved in November 1994, states:

“If physician assisted suicide or voluntary active euthanasia are legal in any jurisdiction, the AGS contends that the strongest protection for patients to make a choice free of coercion should be in place and that it should be illegal for professional caregivers to receive financial compensation for assisting in suicide or euthanasia.”

Not only is the proposed statute an appropriate restriction on its own merits, but it helps to distinguish physician-assisted suicide and euthanasia from good medical care, a distinction which has often been blurred in the cases now before the Supreme Court. These good ends warrant the passage of the statute, but this endeavor falls far short of what is needed.

Prohibiting the use of federal funds to pay for assisted suicide will not alleviate the economic pressure on patients nor the financial incentives on caregivers. Patients who are dying are often poor, often elderly, and often quite disabled. They commonly have very few financial resources and are often profoundly dependent upon the arrangements made for their care by their community. Those arrangements are virtually dictated by Federal funding of Medicare and Medicaid and routinely are so inadequate as to yield terror and unwarranted, untreated pain. Furthermore, even without direct payment for assisting suicide, providers can still have financial incentives to accept early death. Very sick patients are costly in capitated or salaried systems and death prevents the continued accumulation of unpaid charges.

Most important, however, Congress has the opportunity – and the obligation – to set policy to improve care at the end of life. Education and research are largely under federal purview and Congress could mandate improvement. Medicare is the largest purchaser of end-of- life care and should initiate innovation and evaluation, with the goal of tailoring care systems to needs.

My name is Felicia Cohn and I am here representing the American Geriatrics Society. I am a bioethicist on the faculty of The Center to Improve Care of the Dying at the George Washington University. The American Geriatrics Society is comprised of professional health care providers focused upon serving the health care needs of elderly persons and has 6000 dues-paying members.

The American Geriatrics Society agrees with Senate Bill #304. In fact, we have an official policy statement, approved in November 1994, which states:

“If physician assisted suicide or voluntary active euthanasia are legal in any jurisdiction, the AGS contends that the strongest protection for patients to make a choice free of coercion should be in place and that it should be illegal for professional caregivers to receive financial compensation for assisting in suicide or euthanasia.”

The strength of the American moral community and the commitments of healthcare professionals should make it unnecessary to enact a law such as this. No one should be seeking payment for helping to bring about the death of another person. To do so would make ordinary commerce out of situations which should be extraordinary and unsettling. However, Congressional action is appropriate and the American Geriatrics Society supports a statutory bar on payment for assisting in suicide. Not only would this be an appropriate restriction on its own merits, but the statute helps to distinguish physician-assisted suicide and euthanasia from good medical care, a distinction which has often been blurred in the cases now before the Supreme Court.

These good ends warrant the passage of the statute, but this endeavor falls far short of what is needed. Prohibiting the use of federal funds to pay for assisted suicide will keep the taxpayer and the federal government free from direct involvement, but that prohibition will not

alleviate the economic pressure that patients experience nor will it eliminate financial incentives on caregivers for assisted suicide and euthanasia.

Patients who are dying are often poor, often elderly, and often quite disabled. They commonly have very few financial resources and are often profoundly dependent upon the arrangements made for their care by their community. Those arrangements are virtually dictated by Federal funding of Medicare and Medicaid. For most of our patients, their poorest years are those nearest death, when income is low, care needs are high, and lack of community support for personal care during disability takes its largest toll. The prospect of increasing disability and eventual death is disheartening enough, but the added anxiety over the adequacy of the “safety net” of Medicaid services is often terrifying. Having to care for elderly married couples who fear impoverishment of the surviving spouse, or elderly widows who fear the isolation and dependency of Medicaid nursing homes, the members of the American Geriatrics Society are especially concerned that our patients have not been the focus of the discussions over assisted suicide. What, indeed, are we to do when confronted with a patient who claims to want to be dead, precisely because he or she cannot count on having decent care for the time remaining? We voiced this concern in our brief to the United States Supreme Court in the pending cases which argue a Constitutional right to physician assistance in suicide:

“Legalization of physician assisted suicide would create a moral dilemma for geriatricians. Most elderly persons experience serious and progressive illness for extended periods before death and need significant social, financial and medical supports. These resources too often are not available, are of inadequate quality, are not covered by insurance, and are not provided by public entitlement programs. By collaborating in causing early deaths, when continuing to live has been made so difficult, geriatricians would become complicit in a social policy which effectively conserves community resources by eliminating those who need services. By refusing to assist with suicides because a patient’s relative poverty and disadvantaged social situation is seen as coercive, geriatricians would condemn their patients, and themselves, to live through the patient’s undesired difficulties for the time remaining.”

In addition to having no effect upon these coercive financial influences on patients and families, the statute pending before you will not really remove the incentives which might move physicians and health care organizations in the direction of encouraging physician-assisted suicide. Under capitated payment structures in Medicare managed care and under salaried systems like the Veterans' health care system, patients who are very ill are costly to the system. For example, a managed care organization will receive a standard monthly rate for all patients of a given age and gender, say \$350 per month. However, a very sick patient might routinely run up bills of \$3500 per month, for many months. Consider, if you will, a person dying of congestive heart failure who is in the hospital for severe shortness of breath about five days each month for about six months before dying. Relieving itself of this patient will actually result in a net savings of \$2150 per month. Even salaried systems, such as the Veteran's health system, will have financial incentives to accept early death of costly patients. Dying patients are generally costly and time-consuming. Both patients and care providers may feel that assisted suicide will enable them to avoid these burdens. Patients may be led to believe that their choices are limited to enduring the cost and suffering associated with dying or requesting assistance in dying. After all, that is even how two Federal District courts have characterized the situation.

But it is simply not true. In fact, people ordinarily have many alternatives that would ensure a worthwhile existence, despite being near the end of life. Congress has the opportunity to do many important things to improve how we care for the dying. On behalf of our patients, especially the old and frail, the American Geriatrics Society implores Congress to go beyond the current statute and to take on the problems that fuel the calls for physician-assisted suicide and euthanasia. Otherwise, people will continue to suffer while they die and will continue to seek an

end to that suffering. For some, assisted suicide or euthanasia will be inordinately appealing, unless we find ways of eliminating the suffering and assuring that appropriate health care is available.

This Congress should affirm the value of life and the importance of living comfortably and meaningfully, even when life is in its final stages. Despite the fact that three-quarters of Americans die in the Medicare program and more die in other Federal health systems, there is no federal policy and no standards for good care.

Congress should mandate research on care at the end of life, including measuring the quality of care, discerning high-value strategies for providing care, and pursuing biomedical research into issues like the relief of symptoms. Congress also has a special obligation to require improved medical education, since much of physician training is funded through Medicare and other federal programs. Health care professionals are not commonly taught to recognize the dying process, manage symptoms associated with dying, or attend to the special needs of dying patients. Congress can help to ensure better care at the end of life by instituting new requirements for the development of specific provider competencies. If we are to have good lives despite eventually fatal illness, we must devote more attention and funds to learning how to provide excellent supportive care as we die. Congress should lead these efforts.

Right now, nothing is more important than developing responsibility and accountability for quality of care. In most situations, indefensible practices are never examined. No one is held to account for unrelieved pain, for transfers that disrupt care, for the lack of a setting capable of meeting the patient's physical needs, or any of an array of other shortcomings. We have to develop accountability and measurement of quality in end-of-life care. In January, the AGS joined

some three dozen professional and patient-oriented organizations in calling for measurement and accountability for ten aspects of end-of-life care:

- 1. *Physical and emotional symptoms.*** Pain, shortness of breath, fatigue, depression, fear, anxiety, nausea, skin breakdown, and other physical and emotional problems often result in suffering at the end of life. Symptom management is commonly inadequate.
- 2. *Support of function and autonomy.*** Even with inevitable and progressive decline of fatal illness, much can be done to maintain personal dignity and self-respect. More attention is needed to means of achieving increased function and independence.
- 3. *Advance care planning.*** Health care decisions should reflect patient preferences, values, and circumstances. Patient and family experiences can be improved by planning ahead for likely problems.
- 4. *Aggressive care near death.*** Although aggressive care is often justified, many patients might choose to forgo painful, burdensome, or non-beneficial care as they approach the end of life. Additionally, contrary to their preferences, most people will die in institutions during final efforts to extend life. High rates of curative medical interventions near death with low probabilities for success, such as CPR, merit an examination of provider judgment and care system design.
- 5. *Patient and family satisfaction.*** Good medical care means more than prolonging a patient's life. Patient and family perceptions of the decision-making process, the care

- given, the outcomes achieved, and the extent to which opportunities were provided to complete life in a meaningful way are also important.
6. ***Global quality of life.*** Quality of life can be quite good despite declining physical health. Patient assessment of overall well-being may indicate successes and shortcomings in care which are not apparent in more specific measures.
 7. ***Family burden.*** Current and future pressures on funding health care are likely to shift more responsibility for services and payment to families. As this occurs, the financial and emotional effects from the costs of care and the challenges of direct caregiving will affect patient care.
 8. ***Survival time.*** Death may be too readily accepted with constraints on health care resources. Patient survival times vary across plans and provider systems, suggesting priorities and tradeoffs within each which impact the provision of health care.
 9. ***Provider continuity and skill.*** Good end-of-life patient care requires a coordinated effort across care settings to respond to the real needs of dying patients. Enduring relationships between patients and families and professional caregivers are necessary for trust, effective communication, and reliable care plans. The relevant skills, including rehabilitation, symptom control, and psychological support, are necessary to support those relationships.
 10. ***Bereavement.*** The role of health care professionals need not end with the patient's death. The survivors continue to suffer and may benefit from relatively modest interventions.

Finally, Congress should insist upon the development of new programs that better attend to the unique needs of persons sick with eventually fatal illnesses. The AGS and other health care provider organizations have endorsed having the Health Care Financing Administration undertake a test of one such general approach, which we call MediCaring, a program to provide cost-effective, comprehensive, coordinated services for seriously ill Medicare patients facing the end of life.

Currently, the only program for end-of-life care in Medicare is hospice. Yet, hospice serves a very small population. In 1994, hospice provided benefits to 340,000 dying patients in their last few weeks of life. The hospice benefit is limited to people who have a “terminal illness with a life expectancy of six months or less.” Cancer and AIDS are virtually the only diseases that follow a predictable course of decline near death; thus, about 80 percent of hospice patients have cancer and many of the rest have AIDS. Cancer patients are usually referred to hospice when the individual’s functioning declines, usually 3-6 weeks before death. By electing hospice, Medicare patients agree to forgo “life prolonging” interventions and, instead, to receive comprehensive medical and supportive services not otherwise covered by Medicare. In addition to the prognostic requirement, hospice effectively requires that the beneficiary have a home and a family or nursing home caregiver.

Medicare beneficiaries with other diseases – the vast majority of older adults – generally do not have access to hospice care, primarily because their illnesses do not have “predictable” phases of decline at the end of life. This makes a determination of a “6-month” life expectancy difficult. The difficulty of hospice prognostication has recently been highlighted -- to the terror of the many small local hospice programs -- by retrospective reviews conducted by the Office of the

Inspector General in Health and Human Services. The OIG is reviewing only the records of patients who survived more than six months and is making the remarkable inference that many of them were inappropriately admitted. This conclusion is possible only with a blinded review of a mix of records, including some patients who died within six months. The chilling effect on hospice admissions is palpable throughout the land, and Congress may need to become engaged in discerning who was really meant to be served by Medicare hospice programs.

In addition to the constraints of uncertain prognosis, many of our elderly patients are living alone and often in inadequate homes and without substantial support. These patients are not generally eligible for hospice, though they desperately need hospice-like services, including advance planning, support services, symptom management, and coordinated care services – all of which are not generally available.

Providing comprehensive end-of-life care services to these terminally ill individuals should be cost effective and significantly improve quality. About one-fourth of Medicare funds are now spent on care at the end-of-life, and payment is geared toward expensive, high-technology interventions and “rescue” care. Studies show that almost 80% of Americans die in institutions. The rates of pain and adverse symptoms near death are a national disgrace. Most dying patients and their physicians do not discuss death or routinely make advanced plans for end-of-life care.

Under MediCaring, patients with serious and eventually fatal illnesses would be eligible for capitated or otherwise budgeted Medicare providers who would specialize in supportive and palliative services to improve end-of-life care. Care providers would be eligible only if they provided an appropriate array of services and ensured quality of care. Such a program would have several essential components:

1. **Eligibility:** Instead of using a time-based definition of terminally ill, Medicare would establish clinical thresholds for the major diseases leading to death in older persons. These thresholds should represent “life-defining, eventually fatal conditions” and should target otherwise high-cost Medicare patients.
2. **Comprehensive services:** Eligible individuals would receive an array of services that emphasize advance care planning, palliative care, and community-based support services, provided and coordinated by an interdisciplinary team of health care professionals (probably especially from nursing). There would be increased barriers to high-tech “rescue” services. In effect, unnecessary acute care services would be “traded off” for an extensive array of supportive and palliative care, as is done under the hospice program today.
3. **Payments:** The goal would be to offset costs of the additional services by the reduction in unnecessary acute care services. Since the MediCaring program will serve “sicker” patients, payment levels must be set appropriately.
4. **Outcomes:** The participating plans would be responsible for measuring and reporting specific outcomes, including physical and emotional symptoms, advance care planning, aggressive care near death, and patient and family satisfaction.

Congress has the opportunity to significantly affect the possibility for improvements in end-of-life care by directing the Health Care Financing Administration to conduct demonstration projects to learn how to implement innovative approaches like “MediCaring.” We must begin learning how to generate reform so that change will occur sooner rather than later.

Other possibilities abound. Congress could direct that persons beyond a certain threshold of disease are to be “presumed eligible” for Medicaid upon completion of the application, rather than waiting for an official determination, just as is now done for care during pregnancy. Congress could adjust payments for physicians so that continuity is valued more than episodic care, at least for those with established serious illness.

In short, the statute before you has merit. The American Geriatrics Society endorses it. However, no one should think that this is enough. The care of persons at the end of their days in this country is a national disgrace. Much can and should be done, and the Congress has special opportunities and obligations to do so. The American Geriatrics Society stands ready to help in creating an agenda to improve care at the end of life.